Deciding Whether to Continue, Share, or Relinquish Caregiving: Caregiver Views

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Using grounded theory, the authors explore informal caregiving and develop the beginnings of a substantive caregiving theory explaining some of the decision making involved in providing care to an older family member. Sixteen caregivers (CGs) participated in the study. Line-by-line and dimensional analyses reveal various purposes of caregiving for an older family member. These purposes influence whether and how CGs continue to provide the care or decide to share or relinquish caregiving to health care providers. This study suggests that a broader conceptualization of caregiving is needed to illuminate fully the complexity involved in providing care to older adults.

Keywords: *family caregiving, older adults, decision making, grounded theory, care purposes*

Family members are increasingly faced with decisions about whether and how to provide care to aging elderly relatives. For many, this includes decisions about how to continue to provide care as caregiving demands increase. Using data from the National Survey of Families and Household in the United States, Marks (1996) reported that 15.9% of the population had provided care to a family member or a friend in the year preceding the survey, and two thirds of informal care was being provided to elderly individuals. Thus, caregiving to the elderly represents an important proportion of all the care provided in the home. Much of the caregiving literature published during the past two decades has focused on the negative effects that such caregiving has on caregivers. In particular, these studies have focused on the burden and the stress generated by caregiving. (For a review, see Pearlin, Mullan, & Semple, 1990.) Although some work explicitly relates the nature or extent of burden to the likelihood of either sharing or relinquishing caregiving (Whitlatch, Feinberg, & Stevens, 1999), it is clear that many caregivers continue to care well beyond the experience of considerable stress or burden (Aneshensel, Pearlin, & Schuler, 1993).

We currently have little insight into either how informal caregivers providing care to an aging relative are able to continue despite increasing demands and the associated stress or, conversely, what leads other caregivers to relinquish or share

caregiving responsibilities. Understanding these processes is key to providing appropriate support for caregivers who wish to continue, as well as to developing more effective transitions for caregivers and care recipients to new caregiving arrangements. In addition, illuminating the processes that lead to continuing, sharing, or relinquishing caregiving has important implications for public policy and the organization and financing of long-term care services.

Results of the study presented here indicate that continuing to care can be understood only in the context of the relationship between the informal caregiver (a family member) and the care recipient, and is not related to a simplistic match between level of need, or level of stress, and continuing to care. Indeed, for many of the caregivers participating in this study, caregiving was primarily about maintaining a relationship with and for the care recipient, as circumstances threaten their ability to do so. This study also suggests that the complexity of caregiving processes in general remains largely unexplored.

BACKGROUND

The rate of population aging continues to increase (Grunfeld, Glossop, McDowell, & Danbrook, 1997; Hébert et al., 1999; Marks, 1996; Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999). This creates an increasing demand for resources related to care of the elderly and the chronically ill. This increased demand leads to an escalation of public costs as well as to an increase in physical, financial, and emotional costs for those providing the care at home. For instance, it was estimated recently that the cost of dementia care in the United States reached, in 1996, an annual expenditure of more than U.S.$50 billion (Leon, Cheng, & Neumann, 1998). Despite the increased demands on formal health care services, most elder care is provided by family members (Braudy Harris, 1993; Brody, 1985; Cantor, 1991, 1992; Hébert et al., 1999; Horrowitz, 1985; Ory et al., 1999), making the family an important provider. Furthermore, the cost of caregiving on caregivers' physical and mental health (Holicky, 1996; Jutras & Lavoie, 1995; Schulz, O'Brien, Bookwala, & Fleissner, 1995) and financial expenditures (Kramer, 1993; Weinberger et al., 1993) are known to be considerable.

Thus, providing care to an aging family member has significant consequences for caregivers. For instance, researchers have consistently demonstrated that being a caregiver is likely to have a negative impact on caregivers' psychological and physical health (Ory et al., 1999; Pruchno, Kleban, Michaels, & Dempsey, 1990; Scharlach, Runkle, Midanik, & Soghikian, 1994; Schulz et al., 1995). Consequently, considerable research effort has focused on understanding these negative sequelae. Although some researchers have documented the positive consequences of caregiving for caregivers, such as having a sense of accomplishment, feeling appreciated or loved, finding a purpose in life, and feeling closer to the elderly family member, these positive outcomes have generally been neglected. Indeed, stress and/or burden are central features of most caregiving models (e.g., Bergman Evans, 1994; Brown, 1991; Given, Stommel, Collins, King, & Given, 1990; Holicky, 1996; Jutras & Lavoie, 1995; Lawton, Moss, Kleban, Glicksman, & Rovine, 1991; Mittelman et al., 1995; Ostwald, Hepburn, Caron, Burns, & Mantell, 1999; Pearlin et al., 1990; Pruchno et al., 1990; Vitaliano, Russo, Young, Becker, & Maiuro, 1991).

Considering that interventions and health care policies are aimed at enhancing caregivers' well-being and adaptation to their caregiving role, it is understandable that research in this area has focused primarily on understanding the negative consequences at the expense of the more positive consequences of the experience of caregiving (Kramer, 1997). However, focusing exclusively on these dimensions of caregiving precludes the explication of more positive aspects of the caregiving experience. When asked to talk about the caregiving experience, caregivers often share a brighter side of their experience or depict a rather complex picture of caregiving, including both positive and negative aspects of their caregiver role (Farran, Keane-Hagerty, Salloway, Kupferer, & Wilken, 1991; Harris, 1993; Kramer, 1997), showing that there is a need to broaden the conceptualization of caregiving. As noted by Kramer, there is some evidence that caregiving is a far more complex social process than is depicted in the current literature. For instance, researchers and practitioners often anticipate that caregivers seek help when caregiving becomes difficult or when caregivers experience distress. However, high levels of caregiving stress are not associated with an increased inclination to ask for either formal or informal help. Even caregivers who are highly stressed neither ask for nor accept support services (Ganzer & England, 1994). This research suggests a possible inconsistency between perceptions of practitioners and those of caregiving family members regarding help seeking. Although the existence and the extent of this inconsistency have been documented, there is no adequate explanation for it. Furthermore, caregivers provide mixed assessments about the helpfulness of services designed to reduce the burden of caregiving. Why caregivers consider these services to be useful (or not) remains unclear (Gottlieb & Johnson, 2000).

The purpose of the present study is to explore when, how, and under what circumstances caregivers accepted formal assistance with caregiving work as well as what prevented them from doing so. We designed the initial research questions to explore and explain caregivers' understandings of their caregiving work, their views on when they need help, what kind of help is useful for them, and, specifically, how this help is integrated into their overall caregiving work. To learn about how caregivers sought, used, or did not use help, we included in the study an exploration of caregiving work from the perspective of caregivers. For example, we designed the interviews to explore the conditions under which caregiving was or was not perceived by the caregiver to be stressful or burdensome, and how caregivers used, resisted, or declined services, and for what reason(s).

METHOD

We conducted this study using the grounded theory method (Glaser & Strauss, 1967; Strauss, 1987). It is a theory-generating rather than theory-testing method, designed to generate substantive theory from the data. Grounded in symbolic interaction, a psychosociological theory of human action, grounded theory is specifically suited to explore the perspectives of the research participants, leading to theory that is informed by the perspectives of individuals rather than extant disciplinary views, in this case, on caregiving. Furthermore, because the purpose of the study was to explicate caregiving, a complex social process, the grounded theory method was a logical choice (Strauss, 1987).

Sample and Procedures

Using theoretical sampling (Strauss, 1987), we generated a sample of 16 caregivers providing care to an older family member. Each participant was interviewed once, for a total of 16 interviews. Six participants were men caring for their wives, and 10 were women caring either for their husbands (2 participants) or for a parent (6 participants). One female caregiver was providing care to her brother-in-law. As the analysis progressed and the theory developed, other relevant factors guided the selection of the sample (theoretical sample). They included presence or absence of care recipient cognitive impairment, living arrangement, and service use in relation to caregiving. Ten care recipients presented with cognitive impairment (e.g., Alzheimer's disease, early dementia). Seven caregivers shared the same household with the care recipient, and 9 lived in a separate household (e.g., assisted living facility). Four caregivers did not use any services in relation to their caregiving, 6 care recipients were in day centers (from 3 to 5 days a week), 1 caregiver was using home care, 1 was using respite care, and 4 caregivers were using other services (e.g., house cleaning, meal preparation, transportation).

This study received approval from the Committee on Research Involving Human Subjects, University of Wisconsin–Madison. Although there were no anticipated risks related to participating in the study, participants might feel uneasy about answering some of the questions. Thus, we informed participants that if at any time they were uncomfortable with a question asked in the interview, they could refuse to answer. They were also advised that their participation was entirely voluntary, that they could decide not to continue on in the study at any point, and that they could end the interview at any time, for any reason, without sharing that reason with the interviewer. We assured participants that there was no penalty for withdrawal from the study and that participation would have no impact on the delivery of services that they or their aging family member (when applicable) were receiving at the time of the study (or might receive in the future). We dated and signed two copies of the Family Consent Form at the time of the interview. We gave one copy to the participating family caregiver, and the researcher kept the other as a record of the results.

We first recruited caregivers from the Wisconsin Partnership Program (WPP, 5 participants). Because these caregivers already had access to social and health services (e.g., day care center, free medical evaluation, medication management), we hypothesized that these caregivers could talk about how they came to use services: how they "decided to use help" and how they "used services." As the project evolved, we recruited other caregivers outside the WPP to provide additional data regarding use of services. We recruited the remaining participants via the Alzheimer's disease association in the area and by word of mouth (i.e., participants referred other caregivers they knew).

Data Collection

Initial interviews were broad and open ended, to allow participants to define their caregiving in their own words and from their own perspectives. For example, we asked family caregivers to talk about "what it's like to be a caregiver," giving participants the latitude to mention whatever is important or central to their experience.

TABLE 1:   Examples of Evolving Interview Questions Relating to the Category "Defining the Caregiver–Care Recipient Relationship."

Example	*Commentary*
Interviewer: This last thing you just said, that it's like having a two year old . . . *Family caregiver:* a toddler . . . One that can get around. *Interviewer:* A lot of people refer to that, you know, like, "she or he is just like a little kid, or is in a second childhood," or things like that. *Family caregiver:* Yeah. *Interviewer:* I heard people talking about that, and I'm wondering about what happens to a relationship when something like this happens. Did you feel that your relationship to your mother shifted in some ways? How would you describe your relationship right now with your mother?	Interview 4 This daughter spontaneously talked about her interaction with her mother ("it's like having a two year old getting around"). The question asked by the interviewer aimed at understanding how a relationship, developed over a long period of time, can shift because of illness, and how the perception of the relationship may influence the action of providing care.
Family caregiver: Two years of caring for him actually. But I knew him for the prior four years before that. So I've known him for a total of six years. He's become part of my life, you know. *Interviewer:* How would you describe your relationship to him?	Interview 7 To obtain comparative data, the interviewer explored with this sister-in-law her definition of her relationship with the care-recipient. Compared to Interview 4, this relationship was shorter in terms of duration (dimension) and would add to the complexity of the analysis.
Interviewer: People with Alzheimer's disease, over time, they lose their memory and a lot of people say that there is some kind of a shift in their relationship they have with this person. How was it for you? I'm assuming that your relationship with your wife is a little different now than it was maybe before? *Family caregiver:* Well, yes . . .	Interview 12 In this interview, the interviewer initiated the discussion around the relationship between this husband and his wife suffering from dementia. Again, comparative data was obtained about two other dimensions of the relationship that is the nature of the relationship (marital vs. parental vs. others) and the changes over time.

As the research progressed and the theory developed, interview questions become more focused, building on analysis of previous interviews. For example, after three interviews, it became clear that caregiving decisions were influenced by dimensions of the caregivers' relationship to the care recipient. In the subsequent interviews, we designed specific questions to explore how the caregiver–care recipient relationship influenced decision made by caregivers. In Table 1, we illustrate how interview questions were developed from ongoing data analysis and how those questions led to greater complexity of the overall analysis.

Interviewing took place over 7 months. All interviews were audiotaped and transcribed. Interviews lasted between 60 and 90 minutes; most were conducted in the participants' home. (Two were conducted in a research office and one in a restaurant.)

Data Analysis

The transcribed interviews were entered into a computer software, NUD*IST (Non Numerical Unstructured Data Indexing Searching and Theorizing), to manage the data, which we coded using Strauss's (1987) coding paradigm and Schatzman's (1991) dimensional mapping. We used the constant comparative method (Glaser & Strauss, 1967) and a line-by-line dimensional analysis (Caron & Bowers, 2000; Schatzman, 1991) to analyze the data. The analysis focused on the process of caregiving. For instance, we included a description of how, from family caregivers' perspectives, processes of caregiving are understood, the conditions that influence how caregiving is carried out, and the consequences of these understandings for the caregivers, the care recipients, and the caregiver–care recipient relationship.

We applied three levels of coding to the data. First, we used open coding in the early phase of the study (first three interviews). Our aim in this first level of analysis was to uncover all concepts (and their dimensions) related to the process of caregiving that were grounded in the data. At this point, we conducted analysis independently of the order of dimensions or their relationship to each other. This step produced a long list of caregiving dimensions and properties. The second level of analysis, axial coding, resulted in a more complex and integrated analysis. Although axial coding is still considered a form of open coding, it "consists of intense analysis done around one category at a time" (Strauss, 1987, p. 32). Two of the categories grounded in the first three interviews were Making Care Decisions and Defining Purposes of Care. In the subsequent analysis (the next seven interviews), analysis was aimed at uncovering all possible dimensions associated with these two categories and discovering the relationships between (among) their dimensions, while we continued to explore other categories found in the data. Finally, we used the last coding procedure, selective coding, with the remaining interviews to fill in the relationships among dimensions, especially those related to the two central categories describe above, further detailing the relationships between (among) all the dimensions and subdimensions involved in the substantive theory of caregiving.

We used memoing (Bowers, 1989; Strauss, 1987) specifically to keep an ongoing record of data collection and analysis and of theory building. We developed matrixes as analysis proceeded to illustrate and facilitate the development of the theory. The matrixes followed the analysis paradigm (as developed by Strauss, 1987), illustrating the relationships that exists among the categories, dimensions, properties, conditions, and consequences that compose the caregiving theory.

FINDINGS

Defining Caregiving

Early data analysis revealed that when describing caregiving of an older relative, caregivers consistently referred to what they were trying to achieve in addition to the caregiving processes they engaged in to achieve them. As illustrated in the first dimensional matrix (Figure 1), there were two categories of caregiving purpose. The first includes interrelational purposes of caregiving, such as protecting and/or maintaining the caregivers' view of the care recipient's sense of self, as well as the
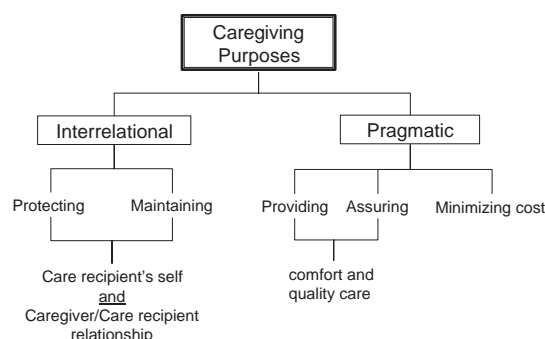
FIGURE 1:   Dimensional Matrix Showing Dimensions and Subdimensions of Caregiving Purposes

caregiver–care recipient relationship. The second category includes purposes that are more pragmatic in nature, such as providing physical comfort and hands-on care, making sure that other caregivers are providing adequate and appropriate care, and minimizing the cost of caregiving.

Although these purposes were reflected simultaneously in care processes for many of the caregivers (i.e., caregivers pursued interrelational and pragmatic purposes at the same time), we present them separately here to simplify the discussion. Caregiving can be distinguished, in many instances, by which of these two categories was the most salient to the caregiving work at a particular time and under specific conditions. Important caregiving transitions were often marked by a shift in the balance of these categories or by a shift in the emphasis from one of these categories to the other. It was at these transition points that caregivers seemed to become more or less receptive to accepting help from others.

Interrelational Caregiving

Interrelational caregiving processes were most likely to be pursued when the care recipient experienced cognitive losses. Under this condition, caregivers often engaged in efforts to bolster the care recipient's sense of self and to preserve the caregiver–care recipient relationship. Interactions between the caregiver and the care recipient were carefully orchestrated by the caregiver to reflect and reinforce "the way things had always been." Past routines were preserved despite a lack of evidence that the care recipient understood them and in the absence of care recipient participation in those processes. For example, one woman, whose mother had lost the ability to communicate, maintained routines and her own interactions with her mother as they had been previously. She explained her actions as "making sure that her mother continued to perceive herself as someone of value." She explained that part of her caregiving was to preserve and maintain her mother's sense of self as a human being and to prevent her from feeling devalued or invisible. Her caregiving was aimed at making her mother "feel recognized as another being, as opposed to feeling invisible, feeling demeaned, diminished, you know, feeling still of value."

Interrelational caregiving processes are designed to protect and maintain the dimensions of the care recipient's view of self that caregivers perceived as

important to care recipients. For example, another daughter caregiver explained how significant being independent was to her mother all her life, and that the daughter was attempting to protect and maintain her mother's sense of independence.

> My mother has always been a very independent person, I couldn't say to her "You can't cook anymore, let me do the cooking." And throughout the whole time I was trying to make her feel like she was independent. She never wanted to live with her children and yet she ended up living with me for a number of years. Particularly because my mother has always been the one that was taking care of somebody else.

"Being the one who was taking care of somebody else" is how the daughter views who her mother was before Alzheimer's disease, and, therefore, what she is trying to maintain. Consequently, protecting and maintaining this dimension of her mother was the goal of her caregiving. This daughter caregiver knew that it would be unacceptable for her mother to be taken care of by her daughter, leading the daughter to hide her caregiving as much as possible. This is consistent with an earlier study in which protecting the care recipient's sense of self was described as "protective caregiving" (Bowers, 1987).

In this study, caregivers developed and used specific strategies to maintain and protect what they determined to be the most important aspects of the care recipient's sense of self. This included assisting care recipients in daily activities in a way that hides caregiving while continuing familiar activities and routines. One daughter, for example, explained,

> I try to back off so that she's not aware if I'm doing quite as much as I'm doing because it bothers her that she's not doing more. One day I just put a bunch of clean dishes in the sink and ran some soapy water and she washed the dishes so she could be doing something.

For this caregiver, the two most important goals were (a) protecting her mother from feeling useless and (b) maintaining a sense of reciprocity in their relationship (so that her mother is able to "do for" the daughter). By "backing off," she can hide from her mother the work she does. Asking her mother to wash the dishes is designed to make her mother feel useful, creating reciprocity in the relationship. In addition to maintaining and protecting those aspects of the self determined by the caregiver to be important, caregivers were protecting and maintaining their relationships with care recipients. This is illustrated in statements such as the following;

> I'm trying to not lose all the relationship I have with my dad, too. I would really be glad to step out for a while and let professionals do some of this if I, so I can preserve some of our friendship and our relationship.

Caregivers engaged in specific caregiving actions to protect the relationship they had with care recipients. This was done for the benefit of both the caregiver and the recipient. For instance, one caregiver decided not to nag the care recipient about preventing future strokes and the complications of a stroke because it was not consistent with their relationship. Assisting the care recipient in this way would alter an important relationship for both of them. Instead, the caregiver relinquished those aspects of the care (e.g., discouraging chewing tobacco, encouraging exercise),

engaging only in activities that would maintain her friendship with the care recipient. She said,

> I kept pushing and pushing—"You've got to do this exercise, you've got to do this or that"—it took me awhile to get to that point of just letting it go. . . . I say where is my friendship if I'm doing that [being pushy] all the time? So that's how I also gave up in doing some things and pushing so hard [forcing him to bath and to exercise, not buying him more tobacco, paying for services] is because then I felt my relationship was eroding.

To understand caregivers' decisions and caregiving actions, it is important to understand what caregivers are trying to achieve. Without such an insight, much of the caregiving work in which these people were engaged could be defined as "noncompliant," not caregiving behavior at all, and dismissed. For this caregiver, discontinuing services could be understood only within the context of protecting and maintaining her relationship with the care recipient. Other caregivers struggled with similar dilemmas.

Interrelational caregiving originates from caregivers' identification of illness-related losses that impair the care recipient's ability to maintain or participate in relationships, and to confirm, through these relationships, who they are. In addition, some caregivers identified important losses for themselves. Thus, for some caregivers, caregiving included maintaining relationships that were important to the caregiver. For instance, one daughter caregiver explained how her mother's loss of cognitive functions resulted in losing a dimension of herself (the caregiver). Her relationship with her mother was important to her and led to the daughter's efforts to support the continuation of that relationship for the daughter's sake as well. She said,

> I've watched her change and our relationship change where I am basically the one taking care of her. She's not the mother that I can rely on anymore. I mean as far as, you know, you go talk to your mother about whatever you want to talk about. She's not there anymore for me to do that. I can go talk to her and I get the relief of talking to her about different things, but it doesn't really sink in to what I am saying. . . . About four or five months ago, I just had this overwhelming desire to see my mother, and I know that it's my mother as she used to be. I thought it was perfectly fine, but it was a day that I don't normally go [to see her] and I just thought I'm going to go down there. I walked in and she just said, "What's wrong?" So there's still something, in her mind, that connects to me, to my needs. And you can't let go of that as long as there's, you know, a form of it still there.

There was evidence that from this daughter's perspective, something remained from her relationship with her mother despite the losses, and she was not willing to let go of the relationship. The daughter wanted to protect and maintain what was "still there," and her actions reflected this desire.

When interrelational caregiving was central, caregivers made decisions that allowed them to pursue interrelational goals. However, in the course of the caregiving experience, caregivers sometimes reached a point in their caregiving where it became difficult or impossible to continue this as the principle focus of their caregiving. This was often found when the caregiver was unsuccessful in maintaining a semblance of the relationship. It was then that a shift to more practical goals occurred. At this point, caregivers often began to redirect their efforts, and they

were more inclined to share and relinquish dimensions of their caregiving with or to health care providers.

Pragmatic Caregiving

When caregiving shifted from providing direct care to sharing the care, caregivers' work shifted as well but was not necessarily any less difficult or demanding. Caregivers' primary purpose was no longer about maintaining a sense of self; it was about making sure the care recipient was physically and emotionally comfortable, although elements of interrelational caregiving continued. Much of this interrelational work was now transferred to health care providers (e.g., writing a list of things caregivers expect would be done by care providers). The family caregiver's work now became focused on monitoring other caregivers to be sure this work was done properly and that the care recipient was emotionally and physically comfortable.

Pragmatic caregiving was aimed at providing physical comfort, assuring high-quality care, and/or minimizing the cost of caregiving. Pragmatic caregiving is primarily about physical dimensions of the care and well-being (e.g., preventing bed pressure sores, making sure care recipients ate well) and focuses on individual emotional dimensions of care (e.g., making sure the care recipient was happy) rather than interrelational dimensions. As two husband caregivers noted,

> At this stage in the illness, in her illness, I'm looking for a facility that will keep her comfortable, um, take good care of [her] in that they will change her clothing and her diapers frequently so that she doesn't develop any rash or develop any pressure points, what I call bed sores. Because at this stage in her life she's totally immobile.

> Yeah, make sure she's comfortable and happy and this and that. . . . That's my real concern. That's she's taken care of, that she receives good care.

At this point, when the focus is no longer on the relationship or on maintaining a sense of self, caregivers were able to think about sharing or relinquishing much of the care. This shift resulted in a new focus on providing comfort or assuring that others would do so (i.e., nurses, paid care workers, nurse aides). Transferring the responsibility for comfort (both physical and emotional) care to others created challenges for caregivers. It required transferring knowledge about how the caregiver understood the care recipient's sense of self. Several caregivers described how it was necessary to make sure that these other care providers knew what was important to the care recipients and acted accordingly. For example, this daughter caregiver explained,

> Though my mom was living there [assisted living facility] and the people there should be taking care of her, when I would go to see her I would find things, like I wrote out this whole list of, you know, "this is what she does, she needs to wear her glasses, she needs to be dressed in this way, da, da, da, da." And I would go, and it would be the middle of the day, and she wouldn't have her glasses on and to me that would be very frustrating.

To achieve this, many caregivers maintained a regular presence in the nursing home. Every caregiver talked about the need to oversee the care provided by other care providers. As stated by a husband caregiver,

I'm out there frequently, I get to know the lead workers in the facility and have developed a good working relationship with them, so that if I have any questions I can ask them, or if I have any comments I can tell them about it. . . . I'm not afraid nor am I bashful about talking about the care or the arrangements about the aspects of her care. I want to know how they are [taking care of her]. I want to know what sort of care they are giving, that's very important.

Being present on a regular basis in the care facility provided this husband with an opportunity to develop a working relationship with the care workers to transfer knowledge necessary to maintain physical and emotional comfort. In getting to know the care workers, he was able to communicate (by asking questions and making comments) the care his wife needed and participate in the "arrangement" of the care. In addition to maintaining a regular presence, caregivers used various strategies to ensure comfort. These strategies included transferring knowledge about care recipients' needs, developing a partnership with care providers, participating actively in the care recipients' care plan, sharing responsibilities of the care with care providers, and duplicating what was delegated to health care providers. These strategies become the primary substance of caregiving work during that phase.

Minimizing the cost of caregiving was the least frequent caregiving purpose pursued by these caregivers. Only one caregiver's work was centered on this specific caregiving purpose. Despite putting up with great amounts of frustration and stress, a daughter caregiver maintained her mother in the home to minimize cost. Although she mentioned that she was starting to think about finding a care facility that would take care of her mother (thus transferring the care over to care providers), this daughter caregiver was purposely avoiding a placement for her mother to minimize the cost of caregiving, saving money for herself and her siblings. She did not want to spend all the money for institutional care.

A Substantive Theory of Caregiving

Findings from this study confirm earlier work suggesting that it is useful to distinguish types of family caregiving by the caregiver's purpose (Bowers, 1987). This study extends this earlier work by revealing that the purpose (and the nature) of family caregiving varies over time and, at least partly, in relation to care recipient characteristics. Furthermore, we have provided insight into when and how family caregivers reject, accept, and/or seek assistance with their caregiving efforts. This research also enlightens us on the consequences of caregiving for both caregiver and care recipient.

As illustrated in the second dimensional matrix (Figure 2), the purpose of caregiving is the salient condition for decisions related to maintaining, sharing, and/or relinquishing care, and accepting or rejecting help is closely tied to the phase in which the caregiver is evolving. These care decisions all involve

- who is going to provide the care (i.e., formal vs. informal caregivers),
- where the care is going to be provided (i.e., at home, in a day care center, a nursing home, etc.), and
- how the care is going to be provided (i.e., exclusive to the family, or shared with or delegated to formal caregivers).
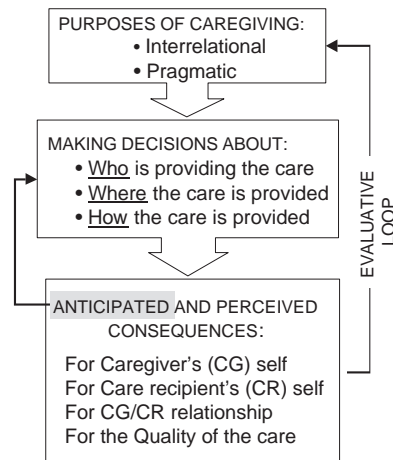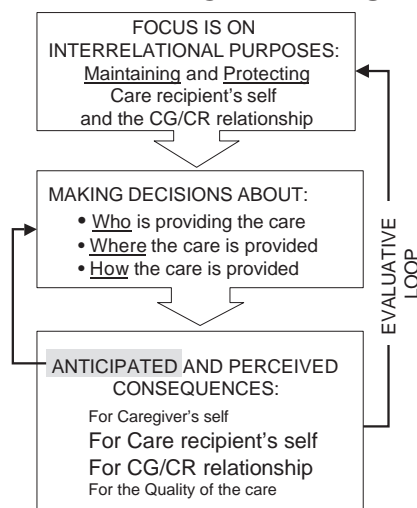
SUBSTANTIVE THEORY OF CAREGIVING

FIGURE 2:   Dimensional Matrix Showing a Substantive Theory About Making Care Decisions Based on Purposes of Caregiving

Results from this study indicate that many caregivers go through at least two phases of caregiving: the interrelational phase and the pragmatic phase (see dimensional matrices shown in Figures 3 and 4). These phases were not necessarily time related. Caregivers often went through them in a nonlinear fashion (i.e., there might be a back-and-forth movement between the phases). During each phase, caregivers made decisions based on the purpose of that phase, and the decision was characterized by anticipating consequences of care strategies.

The interrelational phase (Figure 3) tended to occur early in the experience of caregiving. It is particularly during the interrelational phase that caregivers paid attention to the perceived consequences (i.e., consequences perceived by caregivers) of their caregiving for the care recipients' sense of self and for their relationship to the care recipient. Other perceived consequences remained in the background (i.e., consequences of caregiving on caregiver's self and the quality of the care). The pragmatic phase (Figure 4) is characterized by a focus of the caregiving work on pragmatic purposes. Accordingly, in making caregiving decisions, caregivers' attention shifts to anticipated consequences of caregiving for themselves (i.e., caregivers' self), as opposed to care recipient's self, and to the consequences of the quality of the care (including care recipient's comfort and safety, and skills of others in providing care).

It is worth noting that we identified a third phase in the data analysis, but this remains relatively obscure because we did not explore this phase in depth. Briefly, the results suggest that the third phase is characterized by a focus of the caregiving work almost exclusively on pragmatic purposes, as well as an emotional detachment from care recipients. In this phase, caregiving recedes from the center of caregivers' lives. There were some indications in this study that not all caregivers were able (or wanted) to let go of the relationship they had with care recipients (which characterizes the interrelational phase). Additional research is needed to define this

INTERRELATIONAL PHASE

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┌─────────────────────────────────┐
│          FOCUS IS ON            │
│  INTERRELATIONAL PURPOSES:      │
│   Maintaining and Protecting    │ ◄──┐
│     Care recipient's self       │    │
│   and the CG/CR relationship    │    │
└─────────────────────────────────┘    │
              │                         │
              ▼                         │
┌─────────────────────────────────┐    │
│    MAKING DECISIONS ABOUT:      │    │
│  • Who is providing the care    │    │
│  • Where the care is provided   │    │  EVALUATIVE
│  • How the care is provided     │    │  LOOP
└─────────────────────────────────┘    │
              │                         │
              ▼                         │
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│  ANTICIPATED AND PERCEIVED      │    │
│        CONSEQUENCES:            │    │
│      For Caregiver's self       │────┘
│    For Care recipient's self    │
│    For CG/CR relationship       │
│    For the Quality of the care  │
└─────────────────────────────────┘
```

FIGURE 3:   Dimensional Matrix Showing the Interrelational Phase of Caregiving With Specific Consequences for Care Recipients' Self and for the Caregiver–Care Recipient Relationship

third phase more specifically so that we can understand more completely, for example, the conditions that lead caregivers to enter this phase of caregiving and the consequences to the caregivers and to the quality of care of letting go of the care recipients.
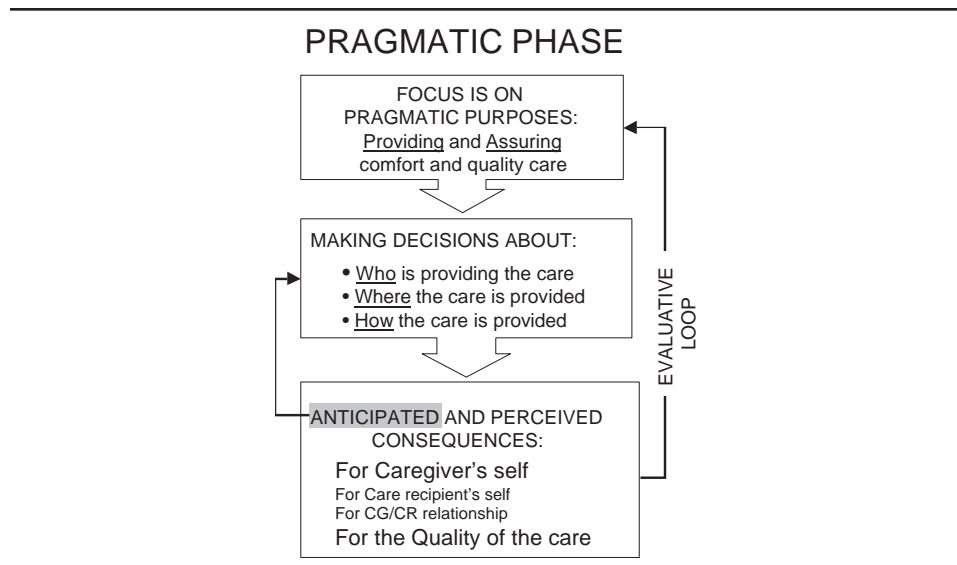
Shifting From the Interrelational Phase to the Pragmatic Phase

Capturing the process of shifting from interrelational to pragmatic purposes was challenging for two reasons. First, there was no particular event that created an obvious shift in the work of caregiving. Second, caregivers described caregiving as a subtle and progressively changing process. As one daughter caregiver said,

> I think that it [caregiving] is a process. I think it's, maybe a lot of times what happens when people get a divorce, sometimes it's like this huge thing and you just say, you know, I can't stand this—your partner goes out with somebody else—but, sometimes it's a series of all these little things and one day you just think "I don't like the way that I am living."

On the other hand, there was some evidence that the shift occurred as caregivers had an increasingly difficult time maintaining and protecting their relationship with care recipients. As quoted earlier, a daughter caregiver began to realize that her relationship with her mother was changing and that her mother could not be there for her in the same way that she used to be, that is, being a mother "you can rely on."

The dimensional matrices shown in Figures 3 and 4 illustrate the difference between the first and second phases of caregiving. It was during a shift from one

PRAGMATIC PHASE

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        ┌─────────────────────────────┐
        │      FOCUS IS ON            │ ◄──┐
        │  PRAGMATIC PURPOSES:        │    │
        │  Providing and Assuring     │    │
        │  comfort and quality care   │    │
        └─────────────────────────────┘    │
                      │                     │
                      ▼                     │
        ┌─────────────────────────────┐    │
        │  MAKING DECISIONS ABOUT:    │    │
        │  • Who is providing the care│    │  E
        │  • Where the care is provided│   │  V
        │  • How the care is provided │    │  A  L
        └─────────────────────────────┘    │  L  O
                      │                     │  U  O
                      ▼                     │  A  P
        ┌─────────────────────────────┐    │  T
        │ ANTICIPATED AND PERCEIVED   │    │  I
        │       CONSEQUENCES:         │    │  V
        │  For Caregiver's self       │ ───┘  E
        │  For Care recipient's self  │
        │  For CG/CR relationship     │
        │  For the Quality of the care│
        └─────────────────────────────┘
```

**FIGURE 4:   Dimensional Matrix Showing the Pragmatic Phase of Caregiving With Specific Conse-
quences for Caregivers' Self and for the Quality of Care**

phase to the other that caregivers made important decisions about caregiving. A shift from one phase to the other reflects important decisions made by the caregiver. These shifts reflect changes not only in terms of the types of caregiving purposes pursued but also in terms of the consequences of caregiving that are relevant to caregivers in each phase. This is a finding of the study that has important implications for our understanding of the caregiving work. In the first phase, caregivers tended to minimize the consequences of caregiving for themselves. This has an important impact on how caregivers make decisions about, for example, using services that would relieve them from the demands of the caregiving work. A daughter caregiver explained why she did not use respite care despite knowing that this type of service could have been beneficial for her. She said,

> I mean I was in tears. I just can't do this. I wasn't so far gone that I would accept anything they would give me. They [nurses at the day care center] said, "Okay we see you're in a crisis point, we want to give you some respite. Your mom can go and stay at this other place for the full weekend, you know, we will take her from here at the end of the day. Take her there and then on Monday morning we will bring her back here." I said, "No, no that's not going to work for her." You see she was not so far gone that she wouldn't know she was in way different place, you know. I said, "I need somebody here, so that she can be in her safe environment. We can get out and get a break, you know, I don't need her to go to another place that is totally unfamiliar and then worry about her all weekend. I don't think that will help." You know, so, so then it was like I was being unreasonable because I wasn't going to take what they would offer. And I said, "But you see what you're offering is not good for my mom, so I can't do that."

Although this daughter caregiver recognized that she needed some respite from the work of caregiving, she was not willing to put her mother in a situation that would make her feel insecure. She was still focused on the purpose of protecting her

mother's self. By deciding not to use respite care for a weekend, this caregiver was not focusing on relieving herself from the work of caregiving; instead, she was focusing on her mother's being in a familiar environment. This quotation illustrates another important point: A decision to not use respite care could be puzzling for health care providers and could be interpreted as caregivers' "resisting help." However, when this decision is taken into the context of pursuing interrelational purposes, it is easier to understand its rationale.

One caregiver was going through a shifting phase at the moment of the interview. She had just made the decision to place her mother in an assisted living facility. On making that decision, she was still focused on interrelational purposes. Explaining the rationale behind her decision, she said,

> I didn't feel like I was nice anymore, you know. Um, I mean that she would call me in my room, and I'm like, "Okay what do you need [impatient tone of voice]? What can I do for you?" Well she couldn't tell me what she needed because what she really needed was me to be there. She didn't need a drink of water, any specific things, like that little kid that keeps calling you in, they want a drink of water. What they really want is they want you there, um, and I heard myself just being harsh. Sounding harsh and I thought, [sigh] I didn't want to do that with her, [voice cracking] with my mom . . . I was hurting her feelings and I was becoming somebody I didn't like in that relationship I had with her.

This caregiver could not maintain her relationship to her mother in a way that would be acceptable for her. Her decision was based on the purpose of protecting her mother's feelings and what was left from her relationship with her mother, and the perceived consequences of her action (i.e., being harsh) on her mother's self and their relationship. This decision initiated a shift in the focus of her caregiving toward more pragmatic purposes.

For many caregivers, it was only when they came to the realization that they could not maintain dimensions of the care recipients' self and/or their relationship to the care recipients that they were willing to explore the consequences of caregiving for themselves (refer to Figure 4). For instance, one daughter caregiver said,

> You, at the time that you are going through it [caregiving at home], you don't realize just how much stress you went through. And when you start to look back on it, you think how in the world did both of us ever get through it? . . . I think you go through a period of denial, and I think no matter how often somebody says "You're not seeing it the way it really is," you're not going to believe them. . . . I didn't know how bad it was for me until she got to the nursing home. It is only then that I started to think about me and how bad it has been for me.

A shift from interrelational to pragmatic purposes was reflected in the discourse of caregivers. In the pragmatic phase, caregivers were not concerned about being with the care recipients; rather, they were concerned about making sure care recipients were well taken care of by other care providers.

Summary

The theory of accepting, rejecting, and seeking assistance with caregiving presented in this article stipulates that not only do caregivers provide care to a family member

with a particular caregiving purpose in mind, they also take into consideration these purposes when making caregiving decisions. Furthermore, we propose that caregiving is characterized by various phases in which the focus of the caregiving purposes shifts over time from interrelational (earlier in the process) to more pragmatic purposes.

DISCUSSION

Within the theoretical framework presented in this study, that is, symbolic interactionism, caregiving is conceptualized as a complex social process that encompasses a broad understanding of the experience of providing care to an aging family member. This caregiving theory is explicit about the importance of knowing the purposes that caregivers are pursuing to interpret the work they do and the caregiving decisions they make.

No study in the current literature could be located exploring the concept of caregiving purposes. Researchers usually conceptualize the work of caregiving in terms of task to be performed (i.e., what caregivers do). For instance, some researchers have conceptualized the work of caregiving in terms of load of care (number of hours), activities of daily living (ADL), and measurement of burden (Gerdner, Hall, & Buckwalter, 1996; Lawton et al., 1991; Miller, 1990). Most of the studies reviewed offered a narrow definition and conceptualization of caregiving. These definitions are very different from what caregivers experienced and reported in this study. In contrast, our participants defined the work or tasks of caregiving in a circular way, reevaluating at different phases the care they provide and the consequences for the care recipient as well as taking into account their shared history with the care recipient.

For the participants of our study, the caregiver–care recipient relationship is central to understanding the processes of caregiving. Even though the concept of caregiving implies two people evolving together and sharing a common experience, it is only in more recent years that a few researchers have looked at the caregiver–care recipient relationship (Knop, Bergman-Evans, & Wharton McCabe, 1998; Kramer, 1993; Kramer & Lambert, 1999; Williamson & Shaffer, 1998). For instance, marital history appears to be an important factor in understanding spousal caregiving. Kramer found that "caregivers who reported poorer quality of the prior relationship also indicated higher level of depression, lower quality of life, and far less satisfaction with caregiving" (p. 371). Knop and colleagues obtained similar results regarding the perceived quality of the marital relationship and depression in caregivers of spouses with Alzheimer's disease. These findings are in agreement with the experiences of male caregivers in this study. Despite numerous relationship losses with their spouse, male caregivers who had satisfactory relationships with their wives before the illness stayed very much involved in providing care to their wives, talked about the rewards of their caregiving, and did not show emotional distress during the interviews. This is one example of a dimension of the relationship that might influence the experience of caregiving for spouses, but the relevance of the caregiving relationship is also important to an adult child taking care of an elderly parent. Clearly, the caregiver–care recipient relationship needs further investigation to better elucidate the complexity of all the processes involved in family caregiving.

There is evidence that although caregivers sometimes express a need for professional assistance, they also show resistance and underutilize supportive formal services (Cohen Mansfield, Besansky, Watson, & Bernhard, 1994; Ganzer & England, 1994; Rudin, 1994). Many of the research studies (Barnes, Given, & Given, 1992; Kosloski & Montgomery, 1994; Rudin, 1994) have focused attention on predicting service utilization based on caregivers' various characteristics (e.g., depression, stress level, perceived burden, health). A few researchers (Bass, Noelker, & Rechlin 1996; Weinberger et al., 1993) have focused on whether the use of these services is effective in relieving caregivers from the strain of the caregiving experience. However, the "underutilization" of service by caregivers seems to be far more complex than is depicted in the literature. In effect, results of this study suggest that a difference in perspective between professionals and caregivers is likely to occur in the early phase of caregiving, when caregivers are most focused on the interrelational purposes of caregiving. In that phase, despite evidence that certain aspects of caregiving might appear stressful or burdensome, caregivers are likely to disregard the taxing aspects of caregiving. It is in the initial phase that caregivers can be perceived (by care professionals) as resisting or denying external formal help, when, in fact, caregivers do not perceive a need for assistance. This is attributed to the fact that in the initial phase, caregivers focus their caregiving on the care recipient's self and/or on their relationship with the care recipients, as opposed to focusing on the consequences of caregiving for themselves. Thus, use of services depends on where (at what phase) caregivers are in the caregiving process. Moreover, in the early (i.e., interrelational) phase, caregivers often perceive neither a need for nor a benefit from formal services. Thus, it is not that they refused or underutilized services, they simply did not perceive or recognize a need for external support or professional attention.

LIMITATIONS OF THE STUDY

This study was a first attempt to describe the work of caregiving in terms of caregiving purposes and provides a foundation on which to expand further. However, we described only two types of caregiving purposes in this study (interrelational and pragmatic). Data analysis reveals that other purposes, pragmatic in nature, were considered by caregivers (e.g., protecting health and preventing hospitalization) in the experience of caregiving and could contribute to conceptual variations of the theory. Relationships between the categories and dimensions of the caregiving theory are being formulated and would benefit from further testing. For instance, the analysis suggested that there is a third phase of caregiving. Because most caregivers interviewed were in the interrelational and pragmatic phases of caregiving, it is not clear if the purposes caregivers pursued in the third phase are the same as or different from the one pursued in other phases and whether they differ only in degree or also in kind. In addition, it can be hypothesized that under the condition that caregivers have a difficult or a negative relationship with care recipients, their purposes in caregiving might differ from those who have a relationship of quality. The inclusion of caregivers describing their relationship as difficult or negative is needed to explain if other purposes of caregiving alter the theory. Finally, the focus of the analysis was on describing caregiving purposes and

how they influence caregivers' decision making. The process of shifting purposes merits more examination. To capture the process of shifting purposes (and, thus, the shifting of caregiving over time), more than one interview with a same participant or interviews with participants at different stages of caregiving are needed.

CONCLUSION

We have shown the importance of broadening the conceptualization of caregiving and have depicted caregiving as a fluid process (as opposed to a linear one). A broader conceptualization will provide researchers with a greater understanding of the many processes involved in providing care to an older family member. These include pursuing caregiving purposes, shifting purposes, caregiving phases, and how these underlie caregiving decisions. This understanding is essential for developing programs of intervention that are tailored to caregivers' needs and lived experiences. For example, to understand the various decisions caregivers make regarding caregiving (e.g., to accept help, to transfer the care over to care providers, to use services), researchers need to consider processes beyond the decision itself and look into the process of making caregiving decisions. In this study, caregivers offered a complex account of all that is involved in the work of caregiving.

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